

## **Appendix B**

### **Descriptions of Data Sources for Health Status Indicators**

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**Parts of this Appendix were reprinted with permission from the *Urban Poverty Database Inventory 1992*, National Center for Children in Poverty, Columbia University, 154 Haven Avenue, New York, NY 10032-1180**

## **CDC Disease Reports-Morbidity and Mortality Weekly Report (MMWR)**

### **Sponsorship**

In 1902, Congress enacted a law directing the Surgeon General to provide forms for the collection and compilation of notifiable disease data for report publications at the national level. In 1961, the CDC assumed responsibility for the collection and publication of data concerning nationally notifiable diseases. Data are collected and compiled from reports to the National Notifiable Diseases Surveillance System (NNDSS), which is operated by the CDC in collaboration with the Council of State and Territorial Epidemiologist (CSTE).

### **Purpose**

Public health officials at state health departments and the CDC collaborate to determine which diseases should be nationally notifiable. The CSTE makes recommendations annually for additions and deletions to the national notifiable disease list on the basis of CDC suggestions. The reporting of nationally notifiable diseases to the CDC by the states is voluntary. Reporting is currently mandated only at the state level. The list of diseases that are considered notifiable varies slightly by state. All states generally report the internationally quarantinable diseases in compliance with the World Health Organization's International Health Regulations. As of January 1995, 49 (see attached for listing) infectious diseases were designated as notifiable at the national level. A notifiable disease is defined by regular, frequent, and timely information regarding individual cases considered necessary for prevention and control of the disease.

### **Content**

The Morbidity and Mortality Weekly Summary Report (MMWR) publication contains summary tables of the official statistics for the reported occurrence of nationally notifiable diseases in the United States. The report is divided into three sections: Part 1 contains information regarding morbidity for each of the diseases considered nationally notifiable during a particular year. The tables provide the number of cases of notifiable diseases reported to the CDC for the year, as well as the distribution of cases by month and geographic location and by patient's age, sex, race, and Hispanic ethnicity. Part 2 contains graphs and maps. These maps depict summary data for many of the notifiable diseases that are described in tabular form in Part 1. Part 3 includes tables that list the number of cases of notifiable diseases reported to the CDC since 1966. It also includes a table enumerating deaths associated with specified notifiable diseases that were reported to the National Center for Health Statistics, during 1984-1993.

### **Design**

After each reporting year, state health department staff finalize case reports for that year with local or county health departments and reconcile the data with reports previously sent to the CDC throughout the year. Notifiable disease reports are published in the annual *Summary of Notifiable Diseases*, only after approval by the appropriate epidemiologist from each submitting state or territory and are the authoritative and archival counts of cases. Data published in the MMWR Surveillance Summaries or other surveillance reports by the CDC programs, which are useful for

detailed epidemiologic analyses, may not agree exactly with data reported in the annual *Summary of Notifiable Diseases* because of differences in the timing of reports, the source of the data, and the use of the different case definitions.

### **Social Geography**

United States resident population.

### **Data Access and Availability**

Provisional data concerning the reported occurrence of notifiable diseases are published weekly in the MMWR. In addition, the MMWR's Journal Articles, Recommendations and Reports from January 1993 to present are available via the Internet at the address below. Surveillance data are presented by the week that they were reported to the CDC by the public health officials in state and territorial health departments because the dates of onset and dates of diagnosis for notifiable diseases may not always be reported. The Recommendations and Reports are published at sporadic intervals depending on the amount of information available at a particular times. Request for further information regarding this data should be directed to the following sources:

Website <http://www.cdc.tov>  
National Center for Health Statistics  
National Center for Infectious Diseases  
National Center for HIV, STD, and TB Prevention (NCHSTP)  
National Immunization Program

### **Representative References**

Centers for Disease Control and Prevention. Summary of Notifiable Disease, United States, 1995. MMWR 1995;44(53).

## **Youth Risk Behavior Survey**

### **Sponsorship**

The Youth Risk Behavior Survey is a national school based survey conducted by the Centers for Disease Control (CDC) and Prevention, National Centers for Chronic Disease Prevention and Health Promotion (NCCDPHP).

### **Purpose**

In 1988, CDC began developing Youth Risk Behavior Surveillance System (YRBSS) to focus the nation on specific behavior that causes the most important health problems among youths, to assess whether this behavior increases, decreases, or remains the same over time, and to provide comparable data among national, state, and local samples of youths.

### **Content**

Questionnaire categorized into six behavior areas: 1) behavior that results in unintentional and intentional injuries; 2) tobacco use; 3) use of alcohol and other drugs; 4) sexual behavior that contributes to unintended pregnancy and STDs, including HIV infection; 5) dietary behavior that results in disease; and 6) physical inactivity. YRBSS currently has three complementary components: national school-based surveys, state and local school-based surveys, and a national household-based survey. Each component provides unique information about different sub-populations of adolescents in the United States.

### **Design**

The first version of the YRBSS questionnaire was completed in October 1989, the second version was completed in November 1989. The short span between the versions reflect the pilot stage of the survey. The questionnaire was used to generate data from national, state, and local samples of students in grades 9-12. Thus far, forty states have participated in this nationally representative random survey. The core questionnaire, 45 minutes in length, is self-administered and contains 84 multiple-choice questions, and has about a grade 7 reading level. A standard computer scannable bubble sheet or questionnaire booklet is used to record responses. Skip patterns are not included in the questionnaire to help ensure that students do not lose their place on the answer sheet when recording responses and to prevent students from looking at other youth's answer sheets or questionnaire booklets to detect a pattern of blank responses that might identify the risk behavior of those students.

## **Social Geography**

Students in grades 9-12.

## **Data Access and Availability**

YRBSS is an epidemiologic surveillance system that shares some of the strengths and limitations of other health-related surveys of youths. Although the YRBSS can provide information to help assess the effects of broad national, state, or local policies and programs, the system was not designed to evaluate the effectiveness of specific interventions, such as teacher training programs, school curriculum, or media campaigns. The National School-Based Survey will be conducted biennially during odd numbered years throughout the decade and will involve national probability samples of students in grades 9-12 from public and private schools. State and local School-Based Surveys will be conducted biennially throughout the decade. Presently, the 1997 survey is available.

## **Future Plans**

Data from the YRBSS will continue to be used to help measure progress, particularly among high school students, toward achieving 26 of the 111 national health objectives that focus on adolescents. In the future, the CDC plans to expand the surveillance system to include components that focus on college students at the national and state levels and middle school students at the state and local levels. In addition, CDC will continue their efforts to increase the quantity and quality of the state and local school based surveys among high school students.

## **Representative References**

Kahn L, Warren CW, Collins JL, Kolbe LJ. Youth Risk Behavior. From Data to Action: CDC's Public Health Surveillance for Women, Infants, and Children. Eds Wilcox and Marks. US Department of Health and Human Services, Public Health Services, Public Health Service, CD; Monograph (vol 3).

## **State Lab Data-Blood lead Levels, Newborn Screening**

### **Sponsorship**

The Center for Disease Control and Prevention (CDC), National Center for Environmental Health (NCEH).

### **Purpose**

NCEH offers laboratory standardization to assure quality programs for laboratories testing dried-blood spots collected on filter paper and to improve the overall quality and precision of laboratory measurements of blood lead.

### **Content**

The Blood Lead Laboratory Reference System (BLLRS) test for childhood lead poisoning level 10ug/dL. The Newborn Screening Quality Assurance Program test for inborn errors of metabolism, sickle cell disease, and other hemoglobinopathies.

### **Design**

Participating laboratories receive three or four pools of blood containing a known amount of lead. These laboratories analyze the blood pools using their usual methods and test their results against target values given by the CDC. The CDC also ships specimens without providing target values. After analyzing the samples, laboratories send their results to the CDC. Then the BLLRS laboratory compares the results with the CDC's target results. A report is sent to the laboratories showing the number of laboratories that participated in the test, the number of test results, the mean of all test results, the mean laboratory bias, the standard deviation, and the CDC's target value. No single laboratory is identified in the report. The BLLRS report allows laboratories to assess their own test results relative to those of participating laboratories and relative to the CDC-assigned target results.

The Lead Poison Prevention Program (LPPP) uses the information from the BLLRS for medical management purposes. This program funds various states, counties, and the District of Columbia, at present there are 41 state, county programs. Detection of positive blood lead levels range from 15-25 ug/dL depending on the reporting state. From July 1995 thru June 1996 reporting period, 2.0 million children were screened thru the LPPP. However, this number does not include unreported screenings. During this period, approximately 34,162 children were put on medical management for a follow up evaluation. Test design for newborn screening is not available at this time.

## **Social Geography**

Children in the participating states, counties, and District of Columbia.

## **Data Access and Availability**

BLLRS information can be obtained at:

BLLRS Coordinator (Mail Stop F-18)  
National Center for Environmental Health  
Centers for Disease Control and Prevention  
4770 Buford Highway, N.E.  
Atlanta, GA 30341-3724

LPPP information can be obtained at:

Jerry Curtis, Public Health Advisor (Mail Stop F-42)  
National Center for Environmental Health  
Centers for Disease Control and Prevention  
4770 Buford Highway, N.E.  
Atlanta, GA 30341-3724

The Newborn Screening is currently under construction.

## **Representative References**

Website      <http://www.cdc.gov/nceh/pubcatns/1994/cdc/fsheet/bllrs.htm#back>  
<http://www.cdc.gov/nceh/programs/lebstden/newborn/newborn.htm>

## **Birth Defects Registries**

### **Sponsorship**

Centers for Disease Control and Prevention's (CDC), National Center for Environmental Health (NCEH) has two systems for assessing the prevalence of birth defects: the Birth Defects Monitoring Program (BDMP) and the Metropolitan Atlanta Congenital Defects Programs (MACDP). In addition, some states have started their own Birth Defects Registries.

### **Purpose**

BDMP's surveillance system is a passive case ascertainment based on hospital discharge summaries of newborns. The proportion of cases it detects depends on the severity of the specific defect. In addition, BDMP provides some limited national data on the occurrence of birth defects.

### **Content**

BDMP includes information on state and county of birth occurrence, year and month of birth, live-born /stillborn status, race sex, birth weight, and 31 International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) procedure and diagnostic codes.

### **Design**

The BDMP uses hospital discharge data on newborns gathered by the Commission on Professional and Hospital Activities (CPHA), based in Ann Arbor Michigan. Data from this system covers both live-born and stillborn infants from 1970 to the present. The data are obtained from a non-random sample of newborn discharge information provided to CPHA by participating member hospitals. CPHA processes these data, conducts range and consistent edit checks for input accuracy. Diagnoses made for readmission are not included, because to do so could introduce duplicate counting of infants.

### **Social Geography**

Births occurring in 1,200 community hospitals throughout the country.

### **Data Access and Availability**

Semi-annually, CPHA provides the CDC with data tapes that include the following information: state and county of birth occurrence, year and month of birth, live-born /stillborn status, race sex, birth weight, and 31 International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) procedure and diagnostic codes. BDMP also provides researchers, policy makers, and the public with time-and-place specific prevalence data.

### **Future Plans**

Most current birth defects surveillance programs, such as the BDMP, make use of hospital records created at the time of birth. Understanding the variations observed in the frequency of birth defects at birth will require a knowledge of the effects of pregnancy terminations that are done as the result of prenatal diagnoses of birth defects. Methods of collecting birth defects data will also need to change to adapt to revisions in hospital data processing. More accessible and affordable data processing



equipment has reduced the number of hospitals that use computer service organizations. These changes will force the CDC to seek new sources of data. The number of hospitals participating in the BDMP continues to decline each year, CDC researchers are investigating new avenues for national birth defects surveillance, including collaboration among states birth defects monitoring programs.

### **Representative References**

1. James LM, Erickson JD, McClearn AB. Prevalence of Birth Defects. From Data to Action: CDC's Public Health Surveillance for Women, Infants, and Children. Eds Wilcox and Marks. US Department of Health and Human Services, Public Health Services, Public Health Service, CD; Monograph (vol 3).
2. Decoufle P, Yeargin-Allsopp M, Boyle CA, Doernberg NS. Developmental Disabilities. From Data to Action: CDC's Public Health Surveillance for Women, Infants, and Children. Eds Wilcox and Marks. US Department of Health and Human Services, Public Health Services, Public Health Service, CD; Monograph (vol 3).

## **Cancer Registries**

### **Sponsorship**

Congress established the National Program of Cancer Registries (NPCR) by enacting The Cancer Registries Amendment Act (Public Law 102-515), in 1992.

### **Purpose**

The Center for Disease Control and Prevention (CDC) is authorized under Public Law 102-515 to provide funds to states and territories, to improve existing cancer registries, to plan and implement registries where they do not exist, to develop model legislation and regulations for states to enhance viability of registry operations, to set standards for completeness, timeliness, quality, and to provide training. In addition, the data set provides an analysis of the cancer burden in the United States on a regional and national basis.

### **Content**

The NPCR enables reporting of cancer data by age, ethnicity, and geographic region (within a state, between states, and between regions. The collected information covers at least 95% of the states' population. The data also contains information on cancer incidence and stage of diagnosis to evaluate the progress toward cancer control in all 50 states and territories.

### **Design**

This population-based registry collects uniform data elements in a standardized format that meets national standards for completeness, timeliness, and quality.

### **Social Geography**

Hospitals, therapeutic radiation facilities, free-standing surgical centers, and pathology laboratories are required by state law or regulation to report cases of cancer.

### **Data Access and Availability**

NPCR is a continuous and systematic collection and analysis of cancer incidence and mortality data. States are supported by NPCR to develop and to collect statewide computerized data and to electronically transmit codes and text to the central registry. NPCR complement existing registries such as the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program. SEER gathers in-depth data on a sample population of five states (Connecticut, Hawaii, Iowa, New Mexico, and Utah) and six metropolitan areas (Atlanta, Detroit, Los Angeles, San Francisco/Oakland, San Jose/Monterey, and Seattle) which covers about 14% of the U.S. population. SEER also monitors trends in incidence, treatment, survival time, and extent of disease. CDC works closely with other federal agencies and national organizations such as the American College of Surgeons (ACS), the National Cancer Registrars Association (NCRA), and other professional organizations to ensure coordinated cancer registry efforts.

Public information is available in the annual National Program of Cancer Registries Program Announcement, and the CDC's Morbidity and Mortality Weekly Reports.

### **Future Plans**

NPCR represents an important step in the evolution of cancer surveillance and an opportunity to strengthen cancer reporting and registration in the United States. When

fully operational, NPCR will collect incidence data on 93% of the United States population. National standardization of data formats and edits will significantly increase the ability to compare the cancer experience from location to location. In addition, the data will be applied to cancer prevention and control programs to evaluate program effectiveness and planning for the future.

### **Representative References**

Website: <http://www.cdc.gov/nccdphp/depe>

## **CDC Abortion Surveillance Data**

### **Sponsorship**

Abortion statistics are compiled by the Centers for Disease Control and Prevention (CDC's) National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), the National Center for Health Statistics (NCHS) and the Alan Guttmacher Institute, an independent nonprofit research organization. NCCDPHP is responsible for national surveillance to document the number and characteristics of women obtaining abortions. NCHS is responsible for compiling abortion data in selected states.

### **Purpose**

Prior to the late, 1970's state health departments had independently developed their own abortion reporting forms or had used fetal death reporting forms which were problematic for reporting induced abortions. In 1977, NCHS with the assistance of the state health departments developed a model abortion form.

### **Content**

The model abortion reporting form collects demographic information and data on gestational age and the type of procedure performed. The form does not include personal modifiers of the women. This form is periodically modified and serves as a primary tool for collecting abortion statistics in most states.

### **Design**

Abortion data compiled by NCHS is collected from participating states and registration areas. Information on each induced abortion is provided to NCHS on magnetic tape as a part of the Vital Statistics Cooperative Program. NCCDPHP compiles tabular data, aggregated at the state and area levels. The last year for reported statistics was 1988 and the reports included data from 14 states and New York City (2). The Alan Guttmacher Institute conducts periodic direct surveys of abortion providers in the United States; however surveys are not conducted annually and do not provide the characteristics of women obtaining abortion.

Each year, in about 45 reporting areas, data are provided from central health agencies. The remaining data are obtained from hospitals and other medical facilities. Patient or physician identifiers are not provided to the CDC. The data are reported by the state in which the abortion occurred. CDC evaluates data for numerical accuracy and for consistency with published reports. CDC computes abortion-to-live-birth ratios by using the number of abortions in a given category (ie. by state, age, or race) as the numerator and the number of live births (reported by state and area health departments) in the same category as denominator. Abortion rates are computed by using the number of abortions as numerators and Current Population Survey data for females aged 15-44 years as denominators.

### **Social Geography**

Data received from 52 reporting areas: 50 states, New York City, and the District of Columbia.

### **Data Access and Availability**

Preliminary annual data on legal induced abortions are published in the Morbidity and Mortality Weekly Report (MMWR), and a final comprehensive report is published in the MMWR's CDC Surveillance Summaries. Each report presents national numbers, ratios, and rates of abortions. The Surveillance Summaries only provide state-specific characteristics of women obtaining abortions. NCCDPHP'S ability to monitor national abortion trends are significantly limited. In 1990, approximately 28% of abortions were reported from states that do not have centralized reporting. These areas could not provide characteristic information of women obtaining abortions. In addition, the number of states that report such information varies from year to year, caution must be used when making temporal comparisons. Nevertheless, the data available from the CDC's abortion surveillance system are particularly useful because characteristic data on women who obtain abortions are not collected by any other national system. NCHS data are from a limited number of states, they cannot be used to represent national statistics. NCCDPHP does not contain demographic data (ie. educational level and area of residence) from the states. The Alan Guttmacher reports higher numbers of abortions in a given year than NCCDPHP. The surveillance situation is dynamic and not completely in the control of the state health agency collecting data because of: multiple levels of reporting, political sensitivities, and legal issues surrounding abortion.

### **Future Plans**

Not all states have recognized the need for state based abortion surveillance, and some states have recognized the need but have been unable to gather information because of the sensitivities that abortion generates. Data on the number and characteristics of women having abortions in all states are needed to have an accurate picture of legal induced abortions in this country.

### **Representative References**

1. Koonin, LM, & Smith, JC. Legal Induced Abortion. From Data to Action: CDC's Public Health Surveillance for Women, Infants, and Children. Eds Wilcox and Marks. US Department of Health and Human Services, Public Health Services, Public Health Service, CD; Monograph (vol 3).
2. Kochanek KD. Induced terminations of pregnancy: reporting states, 1988. Hyattsville, Maryland: US Department of Health and Human Services, Public Health Services, Public Health Service, CDC, NCHS, 1991; DHHS publication no. (PHS)91-1120. (Monthly vital statistics report; vol 39, no. 12, suppl.)

## **Death Files**

### **Sponsorship**

Mortality data from the National Vital Statistics System are produced by the National Center for Health Statistics (NCHS) and state vital statistics offices under the Vital Statistics Cooperative Programs.

### **Purpose**

The basic source of mortality information is the death certificate. United States (U.S.) death registration is a state function. State laws require death certificates for disposition of bodies and for legal purposes (ie. estate settlement). NCHS promotes uniformity in the collection and processing of mortality data.

### **Content**

Mortality data from the National Vital Statistics System provide information on the number of infant deaths by various characteristic of the decedent including age, sex, race, and ethnic origin, and cause of death.

### **Design**

The information on the death certificate is provided by two groups of persons: 1) certifying physician, medical examiner, or coroner certifies the cause of death, and 2) the funeral director provides demographic information (ie. age, race, sex) and files the certificate with the state vital statistics office. Most of the mortality data are coded in the state vital statistics offices according to NCHS's standard procedures. Mortality data are subject to NCHS quality-control procedures at several processing stages to check for completeness, individual item code validity, and consistency between data items. Numbers of deaths are compared between current and previous year's data for each county in the U.S. and for 282 cause-of-death categories. Counts and percentages of records with impossible or out-of-range codes are reviewed and compared with the previous year's performance. Invalid or inconsistent values may be modified or coded unknown.

### **Social Geography**

All mortalities occurring in the United States.

### **Data Access and Availability**

Death certificates are filed and maintained in state vital statistics offices according to state legal requirements. The U.S. Standard Certificate of Death, recommended by NCHS for uses by states, is revised approximately once every 10 years in collaboration with the states, NCHS, other federal agencies, and subject matter experts (2). The current certificate, revised in 1989, has been adopted by the states with minor variations.

### **Representative References**

1. MacDorman MF, Rowley DL, Iyasu S, Kiely JL, Gardner PG, Davis MS. Infant Mortality. From Data to Action: CDC's Public Health Surveillance for Women,

Infants, and Children. Eds Wilcox and Marks. US Department of Health and Human Services, Public Health Services, Public Health Service, CD; Monograph (vol 3).

- 2.** Freedman MA, Gay GA, Brockert JE, Potrzebowski PW, Rothwell CJ. The 1989 revisions of the U.S. standard certificates of live birth and death and the U.S. standard report of fetal death. Am J Public Health 1988;78:168-72.

## **HSDA Mental Health Module**

### **Sponsorship**

The National Household Survey on Drug Abuse is sponsored by the National Institute on Drug Abuse (NIDA) of the Alcohol, Drug Abuse, and Mental Health Administration. The Division of Epidemiology and Preventive Research within NIDA is responsible for the survey.

### **Purpose**

To report the prevalence of mental health problems by demographic categories, the association between these problems and levels of substance use among adolescents and adults.

### **Content**

The 1994 NHSDA included two new modules, one administered to adolescents (12 to 17 years old) and the other to all respondents 18 years or older. The survey items were derived from mental health epidemiologic surveys (2). The adolescent mental health scale focused on the prevalence of self-reported psychosocial problems such as anxiety, attention difficulties and delinquency, and co-occurrence with substance abuse, among the noninstitutionalized adolescent population (This population was comprised of approximately 22 million individuals 12-17 years of age in 1994). The adult mental health module was used to estimate the presence of four mental syndromes over the past 12 months: major depressive episode, panic attack, generalized anxiety disorder, and agoraphobia.

### **Design**

The adult mental health module contained screening questions selected from the University of Michigan's survey instrument version of the Composite International Diagnostic Interview (3). For adolescents, the survey incorporated the widely used 100-item Youth Self-Report Checklist, which ranks individuals on a variety of clinically validated scales of behavioral and emotional problems (4). NHSDA's cross-sectional design does not permit causal conclusions about the relationship between substance abuse, mental syndromes and problems; however, this data does provide a useful complement to other studies.

### **Social Geography**

Adolescents (12 to 17 year olds) and all respondents 18 years or older.

### **Data Access and Availability**

A number of standard publications are issued for each survey: Main Findings, Population Projections, Highlights, and occasional special reports. These publications are available from the Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402.

### **Future Plans**

Surveys are planned dependent on availability of funds.



### **Representative References**

1. National Household Survey on Drug Abuse: Main Findings 1994. Substance Abuse and Mental Health Services Administration, Office of Applied Studies. U.S. Department of Health and Human Services, Public Health Service: DHHS # (SMA) 96-3085, 1996.
2. Details concerning the mental health module, including more extensive reporting of results, can be found in Office of Applied Studies, SAMHSA, (1996) Mental Health Data From the 1994 National Household Survey on Drug Abuse, Advance Report Number 15, Rockville, MD: SAMHSA.
3. World Health Organization (1990) Composite International Diagnostic Interview (CIDI). Version 1.0. Geneva Switzerland; World Health Organization; Kessler RC, McGonagle KA, Zhao S, Nelson C, Hughes M, Eshleman S, Wittchen HU, Kendler KS (1994). Lifetime and 12-Month Prevalence of DSM-III-R Psychiatric Disorders in the United States: Results from the National Comorbidity Survey (NCS). Arch Gen Psychiatry, 51:8-19.
4. Achenbach TM (1991). Manual for the Youth Self-Report and 1991 Profile. Burlington, VT: University of Vermont Department of Psychiatry.

## **Live Birth Files**

### **Sponsorship**

The National Vital Statistics System managed by NCHS, CDC collects and publishes data on births in the United States (2).

### **Purpose**

Over the past four decades, refinements in the birth certificate have helped to improve estimations of the length of pregnancy. The registration of births is a local and state function, but uniform registration practices and use of the records for national statistics have been established over the years through cooperative agreements between the states and NCHS (3). The Local registrar of a town, city, county, or other geographic location collects the records of births occurring in the area. The Vital Statistics System measures critical outcomes such as births and provides exposure information to help identify people at high risk because of geographic, temporal, and personal characteristics (4).

### **Content**

Before 1981, NCHS only computed the period of gestation when a valid month, day, and year of last menstrual period (LMP) were reported on the birth certificate. However, length of gestation could not be determined from a substantial number of live birth certificates each year because the day of LMP was missing. In 1981, NCHS began imputing weeks of gestation for records missing the day of LMP when a valid month and year were provided. The effect of the imputation procedure is to slightly increase the proportion of pre-term births and to lower the proportion of births at 39, 40, 41, and 42 weeks of gestation (5, 6). Major improvements to the vital statistics reporting is reflected in the 1989 revision of the U.S. Standard Certificate of Live Births. It includes a number of new items on medical and lifestyle risk factors related to pregnancy and birth as well as items on obstetric procedures performed, method of delivery, abnormal conditions and congenital abnormalities of the infant, birth attendants, place of delivery, and Hispanic origin of the parents. This major enhancement of medical and health data on mothers and babies greatly expands the scope of information on pregnancy outcomes among both teenagers and adults in the United States (7).

### **Design**

Microfilm copies of the individual records or machine-readable data are transmitted to NCHS for use in compiling the final annual national vital statistics volume (3).

### **Social Geography**

Since 1933, NCHS has obtained information on births from the registrations of all states, New York City, the District of Columbia, Puerto Rico, the U.S. Virgin Islands and Guam (2).

### **Data Access and Availability**

The local registrar of a town, city, county, or other geographic location maintains a local copy, register, or index. Generally, computerized national natality files are available within 18-24 months of the end of the data year. State-level data are available from all of these files and all characteristics are shown by state in published annual natality volumes, Vital Statistics of the United States, Volume I, Natality. In addition, statewide data are usually published annually by each state's statistic unit.

### **Representative References**

1. Blackmore CA, Rowley DL, Kiely JL. Pre-term Birth. From Data to Action: CDC's Public Health Surveillance for Women, Infants, and Children. Eds Wilcox and Marks. US Department of Health and Human Services, Public Health Services, Public Health Service, CD; Monograph (vol 3).
2. Kovar MG. Data systems of the National Center for Health Statistics. Hyattsville, Maryland: US Department of Health and Human Services, Public Health Services, Public Health Service, CDC, NCHS, 1989; DHHS publication no. (PHS)89-1325. (Vital and health statistics series 1, no 23)
3. Pearce ND. Data systems of the National Center for Health Statistics. Hyattsville, Maryland: US Department of Health and Human Services, Public Health Services, Office of Health Research, Statistics, and Technology, NCHS, 1981; DHHS publication no (Vital and health statistics; series 1, no. 16)
4. Wilcox LS, Marks JS. Introduction. From Data to Action: CDC's Public Health Surveillance for Women, Infants, and Children. Eds Wilcox and Marks. US Department of Health and Human Services, Public Health Services, Public Health Service, CD; Monograph (vol 3).
5. NCHS. Vital statistics of the United States, 1988. Vol. 1, Natality. Hyattsville, Maryland: US Department of Health and Human Services, Public Health Services, Public Health Service, CDC, NCHS, 1990.
6. Taffel, S, Johnson, D, Hueser R. A method of imputing length of gestation on birth certificates. Hyattsville, Maryland: US Department of Health and Human Services, Public Health Services, Public Health Service, Office of Health Research, Statistics, and Technology, NCHS, 1982; DHHS publication no. (PHS)82-1367. (Vital and health statistics; series 2, no. 93.)
7. Taffel SM, Ventura SJ, Gay GA. Revised U.S. Certificate of Birth: new opportunities for research on birth outcome. BIRTH 1989; 16:188-93.

## **Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)**

### **Sponsorship**

The Centers for Disease Control and Prevention (CDC), National Center for Environmental Health conducts the MADDSP.

### **Purpose**

To provide regular and systematic monitoring of prevalence rates of selected developmental disabilities according to various demographic, maternal, and child characteristics, in addition to providing a framework and data base for conducting studies of children with selected conditions.

### **Content**

MADDSP is an active, population-based surveillance system for mental retardation, cerebral palsy, and vision and hearing impairment among children aged 3-10 years whose parents are residents of the Atlanta metropolitan area.

### **Design**

Cases are ascertained by reviewing existing educational, medical, and social service records at selected sources within the surveillance system.

### **Social Geography**

Children aged 3-10 years, whose parents are residents of the Atlanta metropolitan area, are monitored for selected developmental disabilities.

### **Data Access and Availability**

Data is not available because MADDSP is a new surveillance system. However, data collection in the MADDS, the prototype for MADDSP, ended in 1990 and some results have recently been published.

### **Future Plans**

The year 2000 national health objectives call for a reduction in the prevalence of serious mental retardation ( $IQ < 50$ ) in school-age children to no more than two cases per 1,000 children (2). Using the data collected in the MADDSP, the CDC can track the progress toward meeting this objective during the 1990's.

### **Representative References**

Decoufle P, Yeargin-Allsopp M, Boyle CA, Doernberg NS. Developmental Disabilities. From Data to Action: CDC's Public Health Surveillance for Women, Infants, and Children. Eds Wilcox and Marks. US Department of Health and Human Services, Public Health Service, Public Health Service, CD; Monograph (vol 3).

Public Health Service. Healthy people 2000: national health promotion and disease prevention objectives-full report, with commentary. Washington, DC: US Department of Health and Human Services, Public Health Service, 1991; DHHS publication no. (PHS)91-50212.

# **National Incidence Study of Child Abuse and Neglect**

## **Sponsorship**

The National Center on Child Abuse and Neglect (NCCAN) established the National Child Abuse and Neglect Data System (NCANDS) to respond to the Child Abuse Prevention and Treatment Act (Public Law 93-247).

## **Purpose**

In 1988, NCCAN embarked on a collaborative effort with the States to collect and analyze annual child abuse and neglect data from child protective services (CPS) agencies in the 50 States, the District of Columbia, the territories, and the Armed Services. In addition, NCANDS Technical Assistance Program helps States to improve their CPS information systems, address technical programmatic issues of submitting data to NCANDS, and enhance the analytical capability of their agencies. The Administration on Children, Youth and Families is committed to providing the most reliable and complete information possible to assist policy makers, child welfare practitioners, and concerned citizens in their efforts to address the problem of child maltreatment. It is hoped that the provided information will help in the development of policies, programs, and services aimed at the protection of the most vulnerable citizens, children.

## **Content**

*Child Maltreatment 1995: Reports From the States to the National Child Abuse and Neglect Data System* (NCANDS) discusses the characteristics of child abuse and neglect investigated by child protective services (CPS) agencies in the 50 States and the District of Columbia. This document is based on child maltreatment data that are aggregated and submitted by the States. The data represent the most complete national information about child maltreatment known to CPS.

## **Design**

The summary data component (SDC) data collection instrument consists of 15 data items on four child maltreatment data topics: report data, disposition data, victim data, and perpetrator data. SDC data collection form and glossary were mailed to the States in the spring of 1996. Data analyzed in this document were collected from all 50 States, the District of Columbia, and the Armed Services. In addition to providing the data, representatives from each State Agency were asked to provide supplementary information or classifications regarding their responses to specific data items. Detailed cases data component (DCDC) is a compilation of case-level data about children who are the subjects of reports alleging child maltreatment. The DCDC permits more detailed analysis of State child abuse and neglect data than is possible with the aggregate data in the SDC. DCDC contains 117 data element including: reports of alleged maltreatment, characteristics of children who are subjects of these reports, types of substantiated or indicated maltreatments, child disabilities, family problems, services provided to victims, and characteristics of perpetrators.

## **Social Geography**

The 50 States, the District of Columbia and the Armed Services.

### **Data Access and Availability**

The report is based on the aggregate data collected through the 1995 SDC. In addition, case-level data collected through the 1995 DCDC are used to elaborate on key SDC findings. A discussion of the DCDC data collection methods and analyses of its data elements may be found in *Child Abuse and Neglect Case-Level Data 1993: Working Pare 1*. Copies of *Child Maltreatment 1995: Reports From the States to the National Child Abuse and Neglect Data System* (NCANDS) are available from the:

National Clearinghouse on Child Abuse and Neglect Information  
P.O. Box 1182, Washington, DC 20013-1182  
1-800-FYI-3366

### **Representative References**

U.S., Department of Health and Human Services, National Center on Child Abuse and Neglect, *Child Maltreatment 1995: Reports From the States to the National Child Abuse and Neglect data System* (Washington, DC: U.S. Government Printing Office, 1997).

Website

<http://www.hhs.gov/cgi.bin/waisgate?WAISdocID=210759573+13+0+0&WAIS>

## **Behavioral Risk Factor Surveillance System**

### **Sponsorship**

The CDC is the federal agency primarily responsible for community-based programs aimed at preventing oral disease and promoting oral health, and for applied research to enhance oral disease prevention within the community.

### **Purpose**

The CDC helps the states and local health agencies collect, analyze, and disseminate data that are specific to their geographic area, and provides leadership in implementing new approaches to oral health surveillance. The CDC has also worked with its state partners to develop a module of questions on oral health for states to include in their Behavioral Risk Factor Surveillance System (BRFSS) surveys. This oral health data permits states to track progress toward the three dental objectives of Healthy People 2000, and provides information for state needs assessment, program planning, and program evaluation.

### **Content**

State and community-based data on oral disease surveillance identifies groups that bear the greatest disease burden and monitors progress in disease reduction. This information enables resources to be targeted to those at risk in states or communities.

### **Design**

In the past two decades, most oral health data have been generated by large national studies designed for research, rather than continuous surveillance. The CDC helps states and local health agencies collect analyze, and disseminate data that are specific to their geographic area, and provides leadership in implementing new approaches to oral health surveillance.

### **Social Geography**

A total of 38 states included the oral health questions in their BRFSS surveys in 1995.

### **Data Access and Availability**

For more information contact:

Centers for Disease Control and Prevention  
National Center for Chronic Disease Prevention and Health Promotion,  
Mail Stop K-64  
4770 Buford Highway NE, Atlanta, GA 30341-3724  
770-488-4751

### **Representative References**

Website      <http://www.cdc.gov/nccdphp/oh/ataglanc>.

## **Poison Control Centers**

### **Sponsorship**

National Clearinghouse for Poison Centers under the direction of the U.S. Department of Health, Education, and Welfare, Food and Drug Administration.

### **Purpose**

The Regional poison information centers function primarily to provide poison information, telephone management and consultation, collect pertinent data, and deliver professional and public education. Cooperation between regional poison centers and poison treatment facilities is the key feature of the program.

### **Content**

The regional PCC identifies treatment capabilities of the treatment facilities and identifies analytical toxicology, emergency and critical care, extracorporeal capabilities within each region to children and to adults. PCC maintain comprehensive poison information resources and comprehensive toxicology information covering both general and specific aspects of acute and chronic poisoning. Each PCC maintains a list of poison center specialty consultants available on an on-call basis. PCC staff includes a medical director, managing director, specialist in poison information, other poison information providers and poison center specialty consultants.

### **Design**

Records of all PCC cases are maintained and handled by individual centers in an acceptable medical record format. The regional poison information center submits all human exposure data to the American Association of Poison Control Centers (AAPCC), National Data Collection System.

### **Social Geography**

United States human population.

### **Data Access and Availability**

The regional poison information center tabulates its experiences for regional evaluation at least once a year. These centers provide information on poisoning management to health professionals, who care for poisoned patients. Public education programs are aimed at educating both children and adults about poisoning dangers and other concepts related to poison control. Directory of Poison Control Centers provides a listing of Poison Control Centers (PCC). Periodically a Directory of Poison Control Centers listing PCC is updated. Information can be obtained from State Departments of Health.

### **Representative References**

National Clearinghouse for Poison Control Centers. Bulletin, Vol 23 (8), 1979. U.S. Department of Health, Education, and Welfare: Bureau of Drugs, Division of Poison Control.

Website      <http://www.pitt.edu/~martint/pages/rpiccrit>.



## **Pregnancy Risk Assessment Monitoring System (PRAMS)**

### **Sponsorship**

Center for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion initiated a cooperative agreement in 1987 with the District of Columbia and several states (Alabama, Alaska, California, Florida, Georgia, Indiana, Maine, Michigan, New York (excluding New York City), Oklahoma, South Carolina, Washington, and West Virginia). The CDC provides these states with financial and technical support for developing, conducting, and maintaining their PRAMS projects.

### **Purpose**

PRAMS is an on-going, population-based surveillance system that obtains self reported behavioral information from new mothers. PRAMS is designed to generate state-specific data and it allows comparisons between states through the use of standardized data collection methods. Currently, PRAMS surveillance covers about one-third of U.S. births.

### **Content**

Information on various topics is collected from new mothers through self-administered questionnaire mailed to them 2-6 months after delivery. Since 1987, eight additional states have participated. The PRAMS questionnaire is structured into two parts: a core portion that is identical for all states, and a state-specific portion. Core questions related to maternal behavior and birth outcomes include focus on the uses of cigarettes and alcohol before and during pregnancy, intendedness of pregnancy, and stressful events during pregnancy. State-specific questions related to maternal behavior before and during pregnancy address such topics as mental health and social support, occupation and physical activity, drug use, and physical abuse. This information is linked to birth certificate data for analysis.

### **Design**

Data is collected by mail with self-administered questionnaire. Telephone follow-ups are conducted for non-respondents. Births in sub-populations with traditionally low-response rates by mail are sampled from the delivery logs of targeted hospitals. Reaching new mothers while they are still in the hospital has provided a feasible and effective method for collecting data from women who are less likely to respond by mail. Data are entered at the state health agency. CDC then weights the data on the basis of sample design, non-response, and omissions from the sampling frame.

### **Social Geography**

New mothers within 2-6 months after delivery.

### **Data Access and Availability**

PRAMS data have been used to estimate the prevalence of behavioral risk factors to assess the effects of behavioral risk factors on infant mortality and birth weight, and to target intervention programs.

### **Future Plans**

PRAMS states are developing analysis projects in collaboration with university faculty, private health promotion organizations, and the CDC. PRAMS data will help states

monitor their progress toward attaining national public health goals by providing state specific data addressing 16 of the 2000 objectives for women and children's health and family planning.

### **Representative References**

Goodwin MM, Bruce C, Zahniser SC, Kogan, MD, Gunter EP, Johnson C. Behavioral Risk Factors Before and During Pregnancy. From Data to Action: CDC's Public Health Surveillance for Women, Infants, and Children. Eds Wilcox and Marks. US Department of Health and Human Services, Public Health Services, Public Health Service, CD; Monograph (vol 3).

Piccinino LJ. Unintended Pregnancy and Childbearing. From Data to Action: CDC's Public Health Surveillance for Women, Infants, and Children. Eds Wilcox and Marks. US Department of Health and Human Services, Public Health Services, Public Health Service, CD; Monograph (vol 3).